

NATIONAL INSTITUTES OF HEALTH
FISCAL YEAR 2003
PLAN FOR HIV-RELATED RESEARCH

XIII: INFORMATION
DISSEMINATION

PREPARED BY THE OFFICE OF AIDS RESEARCH

AREA OF EMPHASIS:

Information Dissemination

SCIENTIFIC ISSUES

Effective and efficient information dissemination and exchange are important tools in the effort to control and end the AIDS epidemic. NIH has responsibility for disseminating information to support research, treatment, and prevention related to HIV and AIDS. Progress in these areas depends on the transfer of information to researchers, health care and service providers, and HIV-infected individuals and their advocates. These audiences have varying needs for information that is critical in the fight against HIV/AIDS. The changing demographics of the epidemic provide challenges to disseminating HIV research results to communities at risk in the United States, including women and minorities, as well as those at risk in developing countries. An additional challenge is providing information in formats that are useful to both health care providers and patients. The flow of information among researchers, health care providers, and the affected communities represents new opportunities to rapidly translate research into practice and to shape future research directions.

A Guide to NIH HIV/AIDS Information Services is updated annually and made available in both printed and electronic form through the National Library of Medicine (NLM) AIDS Home Page (<http://aids.nlm.nih.gov>). This pamphlet provides a comprehensive listing of NIH-supported information services that assist care and service providers, patients, and the public. The electronic version provides links to NIH and Public Health Service (PHS) sites and resources.

TREATMENT GUIDELINES

Access to clinical care guidelines, standards of care, and results of state-of-the-art meetings is critical for physicians and patients. Treatment guidelines for the use of new and complex antiretroviral regimens are continually updated. The guidelines are available in print form and on the Internet Web site of the HIV/AIDS Treatment Information Service (ATIS) (<http://hivatis.org>) (see below). Titles available include the following:

- *Guidelines for the Use of Antiretroviral Agents in HIV-Infected Adults and Adolescents.*
- *Guidelines for the Use of Antiretroviral Agents in Pediatric HIV Infection.*
- *Public Health Service Task Force Recommendations for the Use of Antiretroviral Drugs in Pregnant Women Infected with HIV-1 for Maternal Health and for Reducing Perinatal HIV-1 Transmission in the United States.*
- *Updated U.S. Public Health Service Guidelines for the Management of Occupational Exposures to HBV, HCV, and HIV and Recommendations for Postexposure Prophylaxis*
- *Management of Possible Sexual, Injecting-Drug-Use or Other Nonoccupational Exposure to HIV, Including Considerations Related to Antiretroviral Therapy.*
- *July 2001 Draft USPHS/IDSA Guidelines for the Prevention of Opportunistic Infection in Persons Infected with HIV.*
- *Updated Guidelines for the Use of Rifabutin or Rifampin for the Treatment and Prevention of Tuberculosis Among HIV-Infected Patients Taking Protease Inhibitors or Nucleoside Reverse Transcriptase Inhibitors.*
- *Prevention and Treatment of Tuberculosis Among Patients Infected with HIV: Principles of Therapy and Revised Recommendations.*

ELECTRONIC INFORMATION RESOURCES

Computerized databases and other types of electronic resources are a vital component of NIH AIDS information dissemination, allowing global access to information concerning basic research, clinical trials availability and results, standards of care, and other information of interest to HIV-infected individuals, their care providers, and their advocates. Examples of these critical resources follow.

NLM Databases

Internet: <http://www.ncbi.nlm.nih.gov/PubMed>

MEDLINE/PubMed is available free of charge to users worldwide. The AIDS subset of this database includes citations (with abstracts when available) to AIDS-related journal articles and newsletters. Relevant abstracts from meetings and conferences are included in the new Gateway (<http://gateway.nlm.nih.gov>), which also provides access to other NLM information resources. Descriptions of clinical trials and the agents studied in those trials (AIDSTRIALS and AIDSDRUGS) are accessed through the AIDS Clinical Trials Information Service (ACTIS) Web site, where users may also find supporting materials such as fact sheets and links to published trial results. International, national and state organizations involved in AIDS are found in DIRLINE: (<http://sis.nlm.nih.gov/dirline>).

AIDS Clinical Trials Information Service (ACTIS)

Internet: <http://www.actis.org>

Phone: 1-800-TRIALS-A

E-mail: actis@actis.org

Initiated in 1989, ACTIS is a centralized resource providing information on federally and privately funded HIV/AIDS clinical trials for adults and children at all stages of HIV/AIDS. This free service is jointly sponsored by the National Institute of Allergy and Infectious Diseases (NIAID), NLM, and the Food and Drug Administration (FDA) in collaboration with the Centers for Disease Control and Prevention (CDC). Callers can speak to trained multilingual health specialists who access an AIDS clinical trials database. The ACTIS Web site includes databases that provide information about new and ongoing clinical trials that evaluate experimental drug treatments and candidate vaccines, including descriptions of clinical trials and the agents studied in those trials (AIDSTRIALS and AIDSDRUGS). The Web site also provides HIV vaccine information, supporting materials such as factsheets, and links to published trial results and to other databases. ACTIS collaborates with the ClinicalTrials.gov database (<http://clinicaltrials.gov>) by supplying data and providing links for additional information.

HIV/AIDS Treatment Information Service (ATIS)

Internet: <http://www.hivatis.org>

Phone: 1-800-HIV-0440

E-mail: atis@hivatis.org

NIH collaborated with other PHS agencies to develop ATIS—a toll-free telephone and Web-based reference service for people with HIV disease, their families and friends, and health care providers—to provide information about federally approved treatment guidelines. ATIS is staffed by multilingual health information specialists who answer questions on HIV treatment options using a broad network of Federal, national, and community-based information resources. ATIS is sponsored by NIH, CDC, the Health Resources and Services Administration (HRSA), the Substance Abuse and Mental Health Services Administration (SAMHSA), the Indian Health Service (IHS), and the Health Care Financing Administration (HCFA).

NIH Web Pages

NIH continues to expand and improve its use of the Internet as an important medium for HIV/AIDS information dissemination efforts. NIH Home Pages such as those for NIH overall (<http://www.nih.gov>), Office of AIDS Research (OAR) (<http://www.nih.gov/od/oar>), and all of the NIH ICs and Office of the Director (OD) offices provide extensive HIV/AIDS research and programmatic information for the public, patients, health care providers, scientific investigators, and policymakers. In particular, the NIAID Division of AIDS Web page (<http://www.niaid.nih.gov/daids/>) provides extensive and comprehensive AIDS information. NLM also has created a Web site specifically for HIV/AIDS-related information (<http://aids.nlm.nih.gov>). This site serves as an entry point to many of the HIV/AIDS-related resources available from NIH and serves as a guide to selected resources worldwide.

COMMUNITY OUTREACH PROGRAMS

Providing accurate and up-to-date HIV/AIDS prevention and treatment information to communities at risk, including women and minorities, is a critical challenge. NIH has a number of on-going projects to address HIV/AIDS in minority and underserved communities.

Since FY 1994, NIH, through NLM, has made awards of up to \$40,000 each on an annual basis to enable community-based organizations and public and health science libraries to design their own programs for improving access to AIDS information for targeted groups, including people living with HIV/AIDS, their caregivers, communities at risk, and the general public.

These awards support activities such as purchasing equipment and telecommunications services, implementing Internet access, training in the use of sophisticated information tools, and developing language- and culture-specific materials.

Training in the use of electronic HIV/AIDS resources, including the use of online databases, is included in NIH information dissemination programs. Curriculum-based AIDS information programs and modules are made available nationwide, including through the Historically Black Colleges and Universities (HBCUs) and other groups of minority health professionals, such as the National Association for Equal Opportunity in Higher Education (NAFEO). Training is also being carried out in conjunction with the DHHS Office of Minority Health Resource Center.

NIH HIV/AIDS public education materials include specifically targeted television, radio, and print materials aimed at audiences at high risk for contracting or transmitting HIV infection. Along with six other Federal agencies, NIH has sponsored a series of DHHS satellite broadcasts on HIV/AIDS-related issues. The goal of this series is to make the latest guidelines, data, and information on HIV/AIDS topics available to a wide audience of people interested in HIV/AIDS prevention and care.

Regional Technology Transfer Program

OAR sponsors a series of regional information dissemination programs to bring current research findings to community health professionals, particularly in minority communities, and to populations with the least access to information. This is accomplished through regional workshops and exhibit displays.

Regional Workshops

Meetings in this program have been targeted to Hispanic, Native American, and African American communities. Events also have focused on issues relating to women, children, and injection drug users. Future efforts are now being explored with groups representing Asian and Pacific Islanders and groups representing Latinos. These 2-day events provide a forum for the presentation of prevention and research information. To ensure that the meetings are culturally appropriate and effective, they are planned in collaboration with scientists, researchers, community leaders, people living with HIV/AIDS, and care providers.

Exhibit Displays

OAR has developed two exhibits that offer insight into the HIV/AIDS programs at the NIH that are sent to events in the United States and abroad.

The NIH AIDS Research Program Exhibit provides information about NIH HIV/AIDS programs, including publications, fact sheets, treatment guidelines, information about NIH Web sites, including ATIS and ACTIS, and order forms for information from the Institutes and Centers. The exhibit provides this information to scientists, health care providers, social workers, and community-based workers who may not otherwise be aware of the programs and resources available through NIH.

The Children's Art Exhibit was designed by OAR in collaboration with the Pediatric HIV Working Group of the National Cancer Institute. The exhibit helps individuals better understand the challenges and triumphs of living with HIV and AIDS. The exhibit displays artwork created by children, adolescents, and young adults as part of the art therapy services provided to patients and families participating in the NCI pediatric clinical trials programs.

International Technology Transfer Program

Information and outreach programs for Latin America and the Caribbean have been a key priority for the OAR for many years. OAR has collaborated for the past 10 years with the Office of Continuing Medical Education at the University of Puerto Rico and the AIDS Education and Training Centers of Puerto Rico on a series of meetings on a variety of key AIDS topics. In 2000, in response to Congressional appropriations language encouraging attention to AIDS in the U.S. Virgin Islands, OAR worked with Representative Christian-Christensen to host a meeting on the island of St. Thomas where plenary sessions were satellite broadcast to other Caribbean islands, including the Bahamas, Jamaica, Trinidad and Tobago, and Barbados. Participants on each island viewed the morning plenary sessions and then conducted afternoon workshops to address topics of local interest. Most of the plenary and workshop sessions were captured on video tape and made available for broader viewing and posted on the OAR Web site.

In the last 2 years, the program has been expanded to address critical needs in Africa. In 1999, a meeting on *Education and Training for Community-Based Health Care Workers from Kenya, Tanzania, and Uganda* was held in Nairobi, Kenya. To continue the momentum, a second meeting was held in Mombasa, Kenya, to follow up on the progress of the participants from the first event and introduce a second group of participants.

Collaboration with National Community-based Organizations

OAR collaborates with a number of organizations addressing HIV/AIDS issues in racial and ethnic minority communities: OAR supports approximately 10 regional conferences each year focusing on treatment issues. These meetings are held in locations with the statistically highest HIV/AIDS rates in the United States.

- OAR provides scholarship funds for attendance at the U.S. Conference on AIDS.
- OAR has developed a series of epidemiological videos that have been widely distributed to create a greater awareness of the health care crisis AIDS poses in minority communities. These videos are targeted to African American and Latino communities and are designed to be shown in group settings to encourage dialogue and collective action.
- OAR has developed AIDS Information Kiosks that have been placed in strategic locations to be accessible to the highest at-risk populations, including in community college settings, at the University of Puerto Rico, through grassroots organizations working with youth, and with faith-based organizations. These computer kiosks allow directed searching through the Internet to learn more about HIV and AIDS. The home page and links created for this site direct the user through information on topics they query in English or Spanish.
- For each of the last 2 years, OAR has sponsored a scholarship program that has provided over 200 computers to community-based organizations that use them for their own research and knowledge and make them available to their clients. The computer is available to each successful awardee for 1 year and includes the necessary software, Internet service, telephone access, and training to develop an internal capability to enhance AIDS programs and services through this access. At the end of the year, the organizations have the option of purchasing the hardware and software licenses at reduced prices and assuming the other costs themselves, allowing another group of 100 organizations to be launched into the program.
- Meet the Expert sessions are presentations by experts on specific topics that are broadcast over the Internet, and then followed by a live chat. The entire package of activities is captured on tape and is available for viewing on the OAR Web site.

- OAR has partnered with the International AIDS Society, National Minority AIDS Council (NMAC), and the Indian Health Service to provide access to a number of important meetings through the OAR Web site, allowing a wider audience for these events.
- In partnership with the OAR, the NMAC has established a new program to bring African nongovernmental organizations (NGOs) together with U.S. community-based organizations (CBOs) to share information and experiences about the fight against HIV/AIDS and to forge substantive collaborations. The program is designed to help strengthen capacity, increase program effectiveness, decrease cultural barriers, identify best practices, and build international relationships.

SCIENTIFIC OBJECTIVES AND STRATEGIES

OBJECTIVE:

Support the effective dissemination, communication, and utilization of HIV/AIDS information to all constituent communities of NIH, domestically and internationally.

STRATEGIES:

- Rapidly disseminate new research findings with information on their potential implications for prevention, care, and treatment of HIV-infected individuals, using existing and innovative methods.
- Facilitate the development of HIV prevention and treatment guidelines based on the latest clinical research findings.
- Utilize computer and other information dissemination technology (including the Internet) to disseminate up-to-date HIV/AIDS information; information about HIV therapeutic, vaccine, and prevention trials; and information about HIV training programs.
- Expand access to and education about current state-of-the-art treatment and patient management guidelines, including information on clinical trials, using multiple technologies such as online access and voice access (ATIS and ACTIS).
- Improve current techniques and develop and evaluate new techniques for the two-way communication of information to scientific and lay audiences, particularly to hard-to-reach populations, including information about clinical trials.
- Improve outreach and support access to HIV/AIDS information resources (including computers) by community groups, health care providers, and community-based HIV/AIDS service organizations, including those serving minority communities.
- Work with community-based organizations to develop and promote effective methods of information dissemination in target populations.
- Develop and disseminate educational information to enhance understanding of HIV and basic and clinical research processes by health care providers, community-based HIV/AIDS service organizations, social service organizations, policymakers, and persons with HIV/AIDS.

- Develop and disseminate information resources about HIV vaccine clinical trials and the importance of potential HIV vaccines.
- Evaluate the effectiveness of communication efforts by appropriate means, including obtaining feedback from target audience members through such methods as usability testing of paper and computer interfaces (see www.usability.gov) and information dissemination intermediaries, such as journalists and health educators.
- Promote wide dissemination of the annual NIH Plan for HIV-Related Research and other HIV-related reports as they become available.
- Promote and enhance the exchange of scientific information and communication between public and private research enterprises, such as enhancing communication with the pharmaceutical industry concerning research on the development of therapeutics, vaccines, and microbicides, and working with industrial scientists to make information concerning basic science and HIV protein structures available to the general scientific community.
- Communicate and exchange information internationally on topics such as prevention and treatment, patient management guidelines, and research results that improve the care of HIV-infected individuals, including those in developing countries.
- Support the exchange of basic and applied research information at community, regional, national, and international conferences and workshops.
- Support the cross-collaborations of HIV/AIDS information providers to develop more integrated and comprehensive information dissemination approaches.
- Provide online access to presentation materials, including full text of abstracts and other information (e.g., slides, graphics, plenary presentations) from scientific meetings.
- Collect, archive, and promote use of existing data from NIH-supported basic and applied research for secondary data analysis, including rapid development of public use data sets that can be used for secondary data analysis in NIH-supported studies, especially baseline survey and HIV/STD (sexually transmitted disease) incidence data.

- Widely disseminate information concerning specimen repositories, including existing repositories, specimens available, and relevant information concerning cohorts, contact information, and the process for obtaining access to samples.

OBJECTIVE:

Support research to identify existing gaps in communication approaches, identify and evaluate existing strategies, and develop and test new and innovative communication strategies that will improve access to and use of state-of-the-art HIV information by all relevant target audiences, domestically and internationally.

STRATEGIES:

- Assess the information needs and resources used by various audiences, including biomedical and behavioral research communities, health care providers, service providers, persons living with HIV and their advocates, at-risk populations, scientific and lay media, and the general public.
- Identify obstacles to information dissemination and develop, test, and evaluate possible ways to overcome these obstacles.
- Develop, test, and evaluate innovative strategies for effectively reaching specific audiences (e.g., minority communities, adolescents, drug users, other hard-to-reach populations, and health care providers) with relevant HIV information.
- Investigate how and under what circumstances different communication and dissemination strategies influence the adoption of scientifically based HIV behavior-change interventions and clinical practices in specific audiences.
- Promote use of new technologies and evaluate their effectiveness for disseminating basic and clinical research findings.

OBJECTIVE:

Develop, implement, and evaluate methods of coordination and collaboration on HIV/AIDS communications activities among NIH ICs and with other Federal and non-Federal groups.

STRATEGIES:

- Build and enhance partnerships among CBOs and basic, clinical, and behavioral researchers to encourage exchange of information and experience.
- Promote and foster information dissemination regarding research and programmatic efforts across the ICs, among U.S. Government agencies, and with international partners.
- Promote collaboration among all ICs in providing information about their HIV/AIDS clinical trials to ACTIS and ClinicalTrials.gov.
- Maintain an interface with data sources such as ClinicalTrials.gov to provide information on HIV/AIDS clinical trials, including those for therapies, vaccines, microbicides, and AIDS-related opportunistic infections and malignancies.
- Expand the development of HIV/AIDS resources on the Internet to facilitate national and international research collaboration and data sharing.
- Continue collaborations with the Joint United Nations Programme on HIV/AIDS, the Pan American Health Organization, and other international AIDS agencies or societies on information/communications efforts, including information about international clinical trials.
- Collaborate with public and health sciences libraries, health care providers, AIDS education and training centers, and community-based HIV/AIDS service organizations to facilitate access to needed information.
- Expand collaboration to include academic, medical, and other communities, as appropriate, in the dissemination of NIH HIV-related reports.

APPENDIX A:

NIH Institutes and Centers

NIH INSTITUTES AND CENTERS

NCI	National Cancer Institute
NEI	National Eye Institute
NHLBI	National Heart, Lung, and Blood Institute
NHGRI	National Human Genome Research Institute
NIA	National Institute on Aging
NIAAA	National Institute on Alcohol Abuse and Alcoholism
NIAID	National Institute of Allergy and Infectious Diseases
NIAMS	National Institute of Arthritis and Musculoskeletal and Skin Diseases
NICHD	National Institute of Child Health and Human Development
NIDCD	National Institute on Deafness and Other Communication Disorders
NIDCR	National Institute of Dental and Craniofacial Research
NIDDK	National Institute of Diabetes and Digestive and Kidney Diseases
NINDS	National Institute of Neurological Disorders and Stroke
NIDA	National Institute on Drug Abuse
NIHES	National Institute of Environmental Health Sciences
NIGMS	National Institute of General Medical Sciences
NIMH	National Institute of Mental Health
NINR	National Institute of Nursing Research
NLM	National Library of Medicine
CC	Warren Grant Magnuson Clinical Center
CIT	Center for Information Technology
NCCAM	National Center for Complementary and Alternative Medicine
NCRR	National Center for Research Resources
FIC	Fogarty International Center
CSR	Center for Scientific Review
NCMHD	National Center on Minority Health and Health Disparities
NIBIB	National Institute of Biomedical Imaging and Bioengineering

APPENDIX B:

List of Acronyms

LIST OF ACRONYMS

ART	antiretroviral therapy
ACTIS	AIDS Clinical Trials Information Service
AIDS	acquired immunodeficiency syndrome
AITRP	AIDS International Training and Research Program, FIC
ATI	Analytic Treatment Interruption
ATIS	HIV/AIDS Treatment Information Service
AVEG/HVTN	AIDS Vaccine Evaluation Group/HIV Vaccine Trials Network
BSL	biosafety level
B/START	Behavioral Science Track Award for Rapid Transition
CAB	community advisory board
CBO	community-based organizations
CDC	Centers for Disease Control and Prevention
CFAR	Centers for AIDS Research
CIPRA	Comprehensive International Programs in Research on AIDS
CMV	cytomegalovirus
CNS	central nervous system
CSF	cerebrospinal fluid
CTL	cytotoxic T lymphocytes
DC	dendritic cell
DHHS	Department of Health and Human Services
DNA	deoxyribonucleic acid
DOT	directly observed therapy
EBV	Epstein-Barr virus
FDA	Food and Drug Administration
FIRCA	Fogarty International Research Collaboration Award, FIC
GCP	Good Clinical Practices
GCRC	General Clinical Research Center
GI	gastrointestinal

GLP/GMP	good laboratory practices/good manufacturing production
HAART	highly active antiretroviral therapy
HBCU	Historically Black Colleges and Universities
HBV	hepatitis B virus
HCFA	Health Care Financing Administration
HCV	hepatitis C virus
HERS	HIV Epidemiology Research Study
HHV	human herpes virus
HIV	human immunodeficiency virus
HPTN	HIV Prevention Trial Network
HPV	human papillomavirus
HRSA	Health Resources and Services Administration
HVTN	HIV Vaccine Trials Network
IC	Institute and Center
ICC	invasive cervical cancer
IDU	injecting drug user
IHS	Indian Health Service
IUD	intrauterine device
JCV	JC virus
KS	Kaposi's sarcoma
KSHV	Kaposi's sarcoma herpes virus
LRP	Loan Repayment Program, NIH
MAC	<i>Mycobacterium avium</i> complex
MCT	mother-to-child transmission
MDR-TB	multiple drug-resistant tuberculosis
MHC	major histocompatibility complex
MSM	men who have sex with men
N9	nonoxynol
NAFEO	National Association for Equal Opportunity in Higher Education
NGO	nongovernment organizations

NHL	non-Hodgkin's lymphoma
NHP	non-human primate
NIH	National Institutes of Health
NRTIs	nucleoside reverse transcriptase inhibitors
OAR	Office of AIDS Research, NIH
OARAC	Office of AIDS Research Advisory Council
OD	Office of the Director, NIH
OI	opportunistic infection
PHS	Public Health Service
PML	progressive multifocal leukoencephalopathy
RCMI	Research Center in Minority Institution
RCT	randomized clinical trials
RFIP	Research Facilities Infrastructure Program
RNA	ribonucleic acid
RPRC	Regional Primate Research Center
SAMHSA	Substance Abuse and Mental Health Services Administration
SCID	severe combined immunodeficiency
SHIV	chimeric simian/human immunodeficiency virus
SIT	scheduled intermittent therapy
SIV	simian immunodeficiency virus
SPF	specific pathogen-free
STD	sexually transmitted disease
STI	Structured Treatment Interruption
TB	tuberculosis
TI	treatment interruption
UNAIDS	United Nations Joint Programme on AIDS
VEE	Venezuelan equine encephalitis virus
VRC	Vaccine Research Center
WHO	World Health Organization
WIHS	Women's Interagency HIV Study

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